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ABSTRACT

This catalog was developed to help schools or health personnel train nurses, administrators, teachers, and aides in medical and technological aspects of serving children with complex medical conditions in the educational setting. The first chapter lists resources that document changes in medical care since 1980 and increases in the number of children being assisted by medical supports. It lists overview materials which contain useful information for community providers or administrators about demographic and medical trends which have both a local and a national impact. Chapter 2 identifies sources of information about relevant federal legislation and Supreme Court cases mandating educational services for children with disabilities. Chapter 3 comprises six sections and lists: manuals; information resources on universal precautions; materials on specific technologies (addressing nutrition and medication, elimination, respiration, and equipment); helpful materials for training community personnel; and information on financing and transportation. The last chapter lists state and national resource organizations that can provide support to school systems, individual providers, and families. A brief description of each organization's services is included. Within each section, the materials are listed in chronological order, with the most recent information first. (DB)

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Children Assisted by Medical Technology in Educational Settings:

RESOURCES for TRAINING

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Children Assisted by Medical Technology
in Educational Settings:

RESOURCES FOR TRAINING

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CONTENTS

Page	
5	Introduction
7	How to use this catalog
9	Chapter 1 - Information on children assisted by medical technology
14	Chapter 2 - Issues in education for children with disabilities
22	Chapter 3 - Training materials:
22	Manuals
25	Universal precautions
26	Materials on specific medical technologies -
26	Nutrition and Medication: Central venous lines Gastrostomy tubes Gastrostomy buttons Jejunostomy tubes
31	Elimination: Ostomy care Clean intermittent catheterization

Chapter 3 – (continued)

33 Respiratory:
Oxygen therapy
Tracheostomy care
Ventilators

38 Equipment

40 Helpful materials for training community personnel

44 Information on financing

47 Transportation

48 Chapter 4 - Resource organizations

INTRODUCTION

New challenges face schools as children with increasingly complex medical conditions present themselves for entrance into educational settings. Children with chronic conditions are living longer and fuller lives because of the availability of new medicines and major technical innovations.

To meet these challenges, all school personnel (nurses, administrators, teachers, aides) need training. Many of the medicines and techniques now in routine use were developed so recently, that school nurses may not have encountered them in their prior nursing training. School nurses are called upon to upgrade their clinical skills, inform administrative and teaching colleagues about the new techniques and train and supervise other personnel in specific health procedures.

This booklet was developed to help schools with the training process. The staff of Project School Care gathered resources from around the country and organized this catalog to assist school nurses and others who create and implement student health plans in locating resources and training materials. The catalog offers access to the growing body of literature on health technology assistance. We would welcome suggestions from readers of this catalog on other materials which might be included in a later edition.

Many groups are discovering new and creative ways of enhancing the lives of children with severe, chronic health conditions. By placing these materials together in one catalog, we hope to share with families, or health and education providers the quality resources currently available for these children.

HOW TO USE THIS CATALOG

This catalog is designed to help school nurses and other health personnel provide informed training about children assisted by medical technology. When students enter a school system, it is important that the personnel working with them on a daily basis receive training about the child's health condition and needs. Holding training sessions fosters a staff comfort level concerning the child's school attendance and heightens staff awareness of the resources available to the child and themselves. Training and demystification go a long way to ensure that the child is welcomed to the school, afforded the best possible education, and exposed to the most appropriate socialization opportunities.

The materials listed in this catalog are useful to the health care coordinator preparing general or specific training programs for para-professionals, educators, and community providers. Health personnel may also want to use the resources to update themselves on current developments in clinical health practice.

The first chapter, "Information on children assisted by medical technology," contains resources that document the changes in medical care since 1980 and provides information about the events in health care which have led to the increases in children being assisted by medical supports. This chapter lists overview materials which contain particularly useful information for community providers or school administrators about demographic and medical trends which have both a local and national impact. Chapter 2: "Issues in education for children with disabilities," guides the reader to information about federal legislation and Supreme Court cases that have established mandates for educational opportunities for children with disabilities.

Chapter 3, "Training materials," is comprised of six sections, ranging from manuals to information on the transportation of children assisted by medical technology. In the first section, "Manuals," the reader will find books which provide guidelines for performing specific health procedures. Some of the manuals also emphasize the essential process of working with the school community in preparing for the student's entry into a school program. "Materials on specific technologies" includes technology specific educational materials and is divided into the categories: Nutrition and Medication, Elimination, and Respiratory.

Materials which can be used as handouts at training sessions are listed in the section entitled: "Helpful materials for training community personnel." Some of these materials promote an awareness of the cultural and psychosocial aspects of living with a chronic illness and assistive medical technology. The "Information on Financing" section points the reader toward helpful information about the financing of services for children assisted by medical technology. The final section in this chapter is on "Transportation".

The last chapter, "Resource organizations," lists state and national resource organizations that can provide support to school systems, individual providers, families and children.

Within each section, the materials are listed in chronological order, with the most recent information offered first. The listings are by title so that subject areas can be readily identified.

CHAPTER 1 INFORMATION ON CHILDREN ASSISTED BY MEDICAL TECHNOLOGY

Since 1980, breakthroughs in medicine and surgery have led to significant changes in the availability of specialized techniques for children. The use of procedures such as: hyperalimentation, enteral feedings, supported respiration and clean intermittent catheterization have become much more routine in pediatrics. This has led to longer life-spans for many children with chronic illnesses and an increased demand for sophisticated community services available to support children assisted by medical technology in their homes and schools.

The papers and books in this section review the new developments in health care and nursing. They emphasize the changes that have taken place in the population of children with disabilities and the expectation that, at least for the near future, the number of children being cared for with medical technology will continue to increase.

Information is also provided on the child's transition from hospital to community based care. Experiences with home care of children assisted by medical technology are extensive and the lessons learned are starting to be applied in the school setting. The most important lesson has been that many procedures which were previously restricted to the hospital setting are now performed routinely and safely in the community.

Technology's children: report of a statewide census of children dependent on medical supports.
Palfrey JS, Walker DK, Haynie M, Singer JD, Porter S, Bushey B, Cooperman P.
Pediatrics May 1991, 87:5, p. 611-8.

Primary care of the child with a chronic condition. 1991.
Jackson P, Vessey J.
St Louis, MO: Mosby Year-Book, Inc.

Nursing care of infants and children. 4th ed, 1991.
Whaley L, Wong D.
St. Louis, MO: Mosby Year-Book, Inc.

Local coalitions for coordinating services to children dependent on technology and their families.
Lobosco AF, Eron NB, Bobo T, Kril L, Chalanick K.
Children's Health Care Spring 1991, 20:2, p. 75-86.

The medically complex child: the transition to home care. 1991.
Hochstadt NJ, Yost DM, eds.
New York, NY: Hardwood Academic Publishers.

What's a virus, anyway? 1991.
Fassler D, McQueen K.
Book and video available
Aids Education Collaborative
c/o Otter Creek Associates
86 Lake Street
Burlington, VT 05401.
(802)865-3450

Health care needs and services for technology-dependent children in developmental centers.
Crain LS, Mangravite DN, Allport R, Schour M, Biakanja K.
Western Journal of Medicine Apr 1990, 152:4, p. 434-8.

Critical care nursing: expanding roles and responsibilities within the community.
Bigler BR.
Critical Care Nursing Clinics of North America Sep 1990, 2:3, p. 493-502.

Rural home care for medically fragile children.
Clark J.
Caring Dec 1990, 9:12, p. 32-4.

Guidelines for the delineation of roles and responsibilities for the safe delivery of specialized health care in the educational setting. 1990.
Joint Task Force for the Management of Children with Special Health Needs.
Reston, VA: Council for Exceptional Children (CEC).
Stock #R632.

Trends in pediatric rehabilitation.
Burkett KW.
Nursing Clinics of North America Mar 1989, 24:1, p. 239-55.

Technology-dependent children: the case of children on ventilators in Massachusetts.
Palfrey JS, Haynie M, Porter S, Walker D.
In: Loew RM and Lerner DJ, eds. Mothers, infants and children at risk: monitoring the Massachusetts health care system for groups at risk. 1989, p. 135-9.
Waltham, MA: Massachusetts Health Data Consortium.

Enhancing quality: standards and indicators of quality care for children with special health care needs. 1989.
Epstein SG, Taylor AB, Halberg AS, Gardner JD, Walker D, Crocker AC.
New England SERVE.
Boston, MA: Massachusetts Health Research Institute, Inc.
(617) 574-9493

Telephone assessment of parents' knowledge of home-care treatments and readmission outcomes for high-risk infants and toddlers.
Kun S, Warburton D.
American Journal of Diseases of Children Aug 1987, 141:8, p. 888-92.

Day care for medically fragile children.
Briggs NJ.
Pediatric Nursing Mar-Apr 1987, 13:2, p. 120-1.

Technology-dependent children: hospital v. home care.
A technical memorandum. 1987.
Office of Technology Assessment.
Washington DC: US Congress.
To order: Superintendent of Documents
US Government Printing Office
Washington DC 20402-9325

School children dependent on medical technology.
Palfrey J, DiPrete L, Walker D, Shannon K, Maroney E.
Rehabilitation Research Review 1987.
Washington DC: D:ATA Institute, Catholic University of America.

Surgeon General's report: children with special health care needs.
1987.
U.S. Department of Health and Human Services.
Bureau of Health Care Delivery and Assistance.
Rockville, MD: Division of Maternal and Child Health.

Technology-assisted children: assessing discharge preparation.
Steele NF, Harrison B.
Journal of Pediatric Nursing Jun 1986, 1:3, p. 150-8.

Discharge planning for medically fragile children.
McCarthy S.
Caring Nov 1986, 5:11, p. 38-9, 41.

Home care for the high risk infant: a holistic guide to using technology. 1986.
Ahmann E.
Rockville, MD: Aspen Publishers, Inc.
Includes appendix: Books for parents and professionals.

Children with handicaps: a medical primer. 2nd ed, 1986.
Batshaw ML, Perret YM. Johns Hopkins University School of Medicine.
Baltimore, MD: Paul H. Brookes Publishing Co.
Includes appendices: Resources for children with handicaps; Lifesaving techniques.

Fostering home and community-based care for technology dependent children.
Task Force on Technology Dependent Children.
Washington DC: U.S. Department of Health and Human Services.
(202) 732-1064

Home care for the chronically ill or disabled child: a manual and sourcebook for parents and professionals. 1985.
Jones ML.
New York, NY: Harper & Row, Inc.
Includes appendices: Suggested readings; Helpful organizations.

Chronically ill children and their families: problems, prospects and proposals from the Vanderbilt Study. 1985.
Hobbs N, Perrin JM, Ireys HT.
San Francisco, CA: Jossey-Bass Publishers.

Home care for children with serious handicapping conditions. A report on a conference sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health, Public Health Services. 1984.
Bethesda, MD: Association for the Care of Children's Health.

CHAPTER 2 ISSUES IN EDUCATION FOR CHILDREN WITH DISABILITIES

The federal special education mandate: Individuals with Disabilities Education Act (IDEA, also known as PL 94-142) and the Early Intervention legislation (PL 99-457) are the legal framework and operating structure upon which educational programs for children with chronic disabilities rest. The resources listed below are helpful background materials for training sessions on the special education system, the rights of children with disabilities and the responsibility of school systems. Newly evolving policies for children with HIV infection are also presented in this chapter.

Project School Care: integrating children assisted by medical technology into educational settings.
Palfrey JS, Haynie M, Porter S, Bierle T, Cooperman P, Lowcock J.
Journal of School Health 1992 (in press).

Educating students with severe disabilities in their neighborhood school: the Utah elementary integration model.
McDonnell A, McDonnell J, Hardman M, McCune G.
RASE (Remedial and Special Education) 1991; 12:5, p. 34-45.

Early intervention for technology-dependent infants and young children.
Ahmann E, Lipsi KA.
Infants and Young Children Apr 1991, 3:4, p. 67-77.

Role of the school nurse. 1991.
Caldwell T, Todaro A, Failla S.
In: Caldwell T, Todaro A, & Gates AJ, eds. Community provider's guide: an information outline for working with children with special health care needs (1991 addendum).
New Orleans, LA: Children's Hospital.

Students with special health conditions: an emerging population presents new challenges.
Caldwell TH, Sirvis B.
Preventing School Failure Spring 1991, 35:3, p. 13-8.

Updated medical policy guidelines: children and adolescents with HIV infection/AIDS in school settings. August 1991.
Executive Office of Health and Human Services. Massachusetts Department of Public Health.
Commonwealth of Massachusetts
Boston, MA 02111.

Section 504: a tool for obtaining services for children with special health needs.
Anderson B.
Networking Jan/Feb 1991, p. 6.
Newsletter published by the National Parent Network on Disabilities as an insert in the magazine Exceptional Parent.

Accessing the education system for students who require health technology and treatment. 1991.
Caldwell TH, Kirkhart K
In: Yost DM & Hockstadt N, eds. The medically complex child: the transition to home care, p. 122-39.
New York, NY: Gordon & Breach Science Publishers, Inc.

Where there is a way, there is not always a will: technology, public policy and the school integration of children who are technology-assisted.
Walker P.
Children's Health Care Spring 1991, 20:2, p. 68-74.

To assure the free appropriate public education of all children with disabilities. Thirteenth annual report to Congress on the implementation of the Individuals with Disabilities Education Act. 1991.
Washington DC: U.S. Department of Education and Office of Special Education Programs.
(202) 732-1064

Fast facts on individualized education programs.
Button C.
Cerebral Palsy Association.
Family Support Bulletin Spring 1991, p. 13-14.

Negotiating the special education maze: a guide for parents and teachers. 2nd ed, 1990.
Anderson W, Chitwood S, Hayden D. Parent Educational Advocacy Training Center.
Rockville, MD: Woodbine House.
Includes appendices: State offices; National organizations concerned with disabled persons; Selected reading list.

Development of a preschool program for tracheostomy dependent children.
Sherman LP, Rosen CD.
Pediatric Nursing Jul-Aug 1990, 16:4, p. 357-61.

P.L. 94-142 and P.L. 99-457: considerations for coordination between the health and education systems.
Morse M.
Children's Health Care 1990, 19:4, p. 213-8.

Providing therapeutic services in various educational settings: an analysis of the related services provision of PL 94-142 in five urban school districts.
Palfrey JS, Singer JD, Raphael ES, Walker DK.
Pediatrics 1990, 85, p. 518-25.

How schools work and how to work with schools: a guide for health professionals. 1990.
Earle J, Kane W, Sullivan C.
Alexandria, VA: National Association of State Boards of Education.
(703) 684-4000

Laws affecting children with special needs. Selected Federal statutes and regulations. 1990.
Walsh S, McKenna P.
LRP Publications.

Providing education to students with complex health care needs.
Lehr DH.
Focus on Exceptional Children Mar 1990, 22:7, p. 1-12.

AIDS/HIV: the role of the school nurse. 1990.
National Association of School Nurses, Inc.
(201) 883-2117

Medical problems of students with special needs: a guide for educators. 1989.
Holvoet JF, Helmstetter E.
Boston, MA: Little, Brown and Co.

Meeting the needs of infants and toddlers with handicaps: federal resources, services and coordination efforts in the departments of Education and Health and Human Services. 1989.
Washington DC: Department of Education and Department of Health and Human Services.
(202) 732-1064

Someone at school has AIDS: a guide to developing policies for students and school staff members who are infected with HIV. 1989.
Fraser K.
Alexandria, VA: National Association of State Boards of Education.
Includes appendix: Ordering information for publications mentioned in this document.

Students with special health care needs.
Sirvis B.
Teaching Exceptional Children 1988, 20:4, p. 40-4.

Recommendations: services for children with special health care needs. 1988.
Task Force on Children with Special Health Care Needs.
Des Moines, IA: Iowa Department of Education.
(515) 281-3176

Federal law guaranteeing handicapped children a free and appropriate public education successful in transforming local school programs. 1988.
Butler JA, Palfrey JS, Singer JS, Walker DK, Raphael ES.
Serving handicapped children: a special report.
Princeton, NJ: The Robert Wood Johnson Foundation.
(609) 452-8701

The implementation of health related procedures in classrooms for students with severe multiple impairments.
Mulligan-Ault M, Guess D, Struth L, Thompson B.
Journal of the Association for Persons with Severe Handicaps 1988, 13:2, p. 100-109.

AIDS education in the schools: a literature review as a guide for curriculum planning.
Brown L, Fritz G.
Clinical Pediatrics July 1988, 27:7, p.311-316.

Helping schools to cope with AIDS.
Grady M.
Medical Aspects of Human Sexuality Jan 1988, 22:1, p. 24, 26-27, 31-32.

Health services as "related service" under P.L. 94-142, the Education for All Handicapped Children Act. 1988.
Beyer H.
Unpublished paper. N. Neal Pike Institute for the Handicapped.
Boston University School of Law
765 Commonwealth Avenue
Boston, MA 02215

Report accompanying the Education of the Handicapped Act Amendments of 1986 (House Report #99-860) and commenting on P.L. 99-457. 1987.
Gilkerson L, Hilliard AG, Schrag E, Shonkoff JP.
National Center for Clinical Infant Programs.
733 15th Street, N.W., Suite 912
Washington DC 20005
(202) 347-0308

Medically fragile students pose dilemma for school officials.
Viadero D.
Education Week 1987, 1, p. 14.

Health impaired children deserve a break.
Shayne MW, Walker DK, Perrin JM, et al.
Principal, 1987 66:1, p. 36-9.

School health services after Tatro.
Vitello SJ.
Journal of School Health 1987, 57:2, p. 77-80.

Health and special education: a study of new developments for handicapped children in five metropolitan communities.
Palfrey JS, Singer JD, Walker DK, Butler JA.
Public Health Reports Jul-Aug 1986, 101:4, p. 379-88.

Making things better for chronically ill children: a guide for schools and families. 1986.
Lynch E, Murphy D, Lewis R. San Diego State University.
Sacramento, CA: California State Department of Education.

Chronically ill children in early childhood education programs.
Walker DK.
Topics in Early Childhood Special Education 1986, 5:4, p. 12-22.

P.L. 94-142: impact on the schools. 1985.
Weiner R.
Arlington, VA: Capitol Publications.
Includes: national and state telephone directories.

How the courts have interpreted the related services mandate.
Osborne Jr A.
Exceptional Children 1984, 51:3, p.249-252.

Education and chronically ill children: a need-based policy orientation.
Ashcroft SC.
Peabody Journal of Education 1984, 61: 2.

The views of school principals and teachers on the role of the school nurse with handicapped students.
Goodwin LD, Keefe MR.
Journal of School Health 1984, 54:3, p. 105-9.

Care of chronically ill children in schools.
Walker DK.
Pediatric Clinics of North America 1984, 31:1, p. 221-33.

Chronically ill children in school.
Walker DK, Jacobs FH.
Peabody Journal of Education 1984, 6:2, p. 29-74.

Regulation and schools: the implementation of equal education for handicapped children. Hargrove EC, Graham SG, Ward LW, Abernethy V, Cunningham J, Vaughn WK.
Peabody Journal of Education 1983, 60: 4.

A free appropriate public education.
Beyer HA.
Western New England Law Review 1983, 5, p. 363-90.

National Association of State School Nurse Consultants define the role of the school nurse in "P.L. 94-142 Education for All Handicapped Children Act of 1975."
Hertel V, Brainerd E, Desrostus C, Hatfield ME, Lewis P, Quinne HN.
Journal of School Health 1982, 54, p. 475-478.

Educating the chronically ill child. 1982.
Kleinberg SB.
Baltimore, MD: Aspen Publications.

The Education of All Handicapped Children Act (PL 94-142): new responsibilities and opportunities for the school nurse.
Rose TL.
Journal of School Health 1980, 50:1, p. 30-1.

CHAPTER 3 TRAINING MATERIALS

In recognizing the needs of children with technology dependency in the community, a number of groups have developed helpful training manuals and guidelines for the provision of health care in schools and other community settings. The most current and comprehensive of these are listed in this section. The following sections include procedure-specific educational materials which may augment the larger manuals and may be adapted for handouts and presentations. Several of the manuals include sheets appropriate for use in training sessions and checklists for monitoring of a direct provider's health care skills.

MANUALS

Community provider's guide: an information outline for working with children with special health needs. 1991 revision.
Caldwell TH, Todaro AW, Gates AJ, eds.
New Orleans, LA: Children's Hospital.
Includes sections on intermittent catheterization; gastrostomy feedings; suctioning - oral, nasal, tracheal.

Supervisor's guide for transporting children with special health needs. 1991.
Baltimore, MD: Maryland State Department of Education and Maryland State Department of Health and Mental Hygiene.

Guidelines and procedures for meeting the specialized physical health care needs of pupils. 1990.
Sacramento, CA: California State Department of Education.
This manual provides a summary of state and federal laws defining the specialized physical health care services that schools must provide, step-by-step instructions for performing specific procedures, advice on setting up a care system, forming administrative teams and keeping records, definitions of the various kinds of physical handicaps for which special services are to be provided and recommendations for preventing the spread of infectious diseases.

Children assisted by medical technology in educational settings: Guidelines for care. 1989.
Haynie M, Porter SM, Palfrey JS.
Boston, MA: Children's Hospital.
Includes sections on gastrostomy feedings; central venous lines (CVLs); ostomy care, intermittent catheterization; oxygen; nasogastric feedings; suctioning - oral, nasal, tracheal; children assisted by ventilators; universal precautions.

Emergency medical treatment: children. 1989.
Vogel S, Manhoff D.

Emergency medical treatment: infants. 1989.
Vogel S, Manhoff D.
To order: Scott Thoe, President
RPM International
P.O. Box 616
Oshkosh, WI 54902
(800) 233-2122

Procedure guidelines for health care of special needs students in the school setting. 1988.
Viele, E.
Denver, CO: Colorado Department of Education and Colorado Department of Health.
Includes sections on gastrostomy feedings; nasogastric feedings; intravenous nutrition; oxygen; suctioning - oral, tracheal; intermittent catheterization; universal precautions.

Managing the student with a chronic condition: a practical guide for school personnel. 1988.
Larson GL.
Wayzata, MN: DCI Publishing.
Includes sections on gastrostomies; ostomies; intermittent catheterization; tracheostomy care; suctioning - tracheal; universal precautions.

Getting it started and keeping it going: a guide for respiratory home care of the ventilator assisted individual. 1987.
Manual with accompanying video.
Ventilator Assisted Care Program and Respiratory Care Department.
New Orleans, LA: Children's Hospital.
Includes sections on tracheostomy care; suctioning - oral, nasal, tracheal; oxygen; children assisted by ventilators.

Administrative guidelines for school districts for the development of policies and procedures pertaining to the administration of first-aid, emergency care, medications and treatments. 1983.
Pennsylvania Department of Health.
Harrisburg, PA: Commonwealth of Pennsylvania.

Manual of school health. 1986.
Lewis K, Thomason H.
Menlo Park, CA: Addison-Wesley Publishing Co.

Children's Hospital infection control manual. October 1991.
Boston, MA: Children's Hospital.

Updated medical policy guidelines: children and adolescents with HIV infection/AIDS in school settings. August 1991.
Executive Office of Health and Human Services. Massachusetts Department of Public Health.
Boston, MA 02111.

Practical guidelines for reducing the risk of communicable disease in a school setting. 1990.
Bauer D, Ashworth V, Hootman J, Fenton G.
School Health Services, Division of School Support Services.
Portland, OR: Multinomah Education Service District.

Guidelines for prevention of transmission of human immunodeficiency virus and hepatitis B virus to health-care and public-safety workers.
Centers for Disease Control.
Morbidity and Mortality Weekly Report 1989, 38:6S, p. 1-37.

Guidelines for effective school health education to prevent the spread of AIDS.
Centers for Disease Control.
Morbidity and Mortality Weekly Report 1988, 37:S-2, p. 1-13.

Update: universal precautions for prevention of transmission of human immunodeficiency virus, hepatitis B virus, and other airborne pathogens in health care.
Centers for Disease Control.
Morbidity and Mortality Weekly Report 1988, 37:24, p. 377-382, 387-388.

NUTRITION AND MEDICATION

Central Venous Lines

The PIC catheter.
Rountree D.
American Journal of Nursing 1991, p. 22-26.

An implantable venous access device for children.
Kandt K.
Maternal Child Nursing Journal Mar-Apr 1991, 16:2, p. 88-91.

Central venous access devices in children.
Marcoux C, Fisher S, Wong D.
Pediatric Nursing Mar-Apr 1990, 16:2, p. 123-133.

Information for teachers of children with central venous catheters.
Dufour DF.
Pediatric Oncology Nursing 1990, 7:1, 37-38.

Your complete guide to central venous catheters.
Viall CD.
Nursing 90 Feb 1990, p. 34-41.

Family participation in the care of central venous lines.
Pike S.
Nursing (London) June 1989, 3:38, p. 22-5.

Growing with home parenteral nutrition: adjusting to family life and child development. (Part 1 of a two-part series.)
Berry RJ, Jorgensen S.
Pediatric Nursing Jan-Feb 1988, 14:1, p. 43-5.

Teacher's reference on right atrial catheters.
Meeske K, Davidson LT.
Journal of Pediatric Nursing 1988, 3:5, 351-353.

The how-to's of home IV therapy.
Wildblood RA, Strezo PL.
Pediatric Nursing Jan-Feb 1987, 13:1, p. 42-6, 68.

I.V. therapy: home care manual. 1987
Kruzic P, Grundfast D, Stites L, John E.
Hospital Home Health Care Agency of California.
Rockville, MD: Aspen Publishers, Inc.
Includes a suggested reading list.

Experience with a totally implanted venous access device in children with malignant disease.
Bagnall H, Ruccione K.
Oncology Nursing Forum Jul-Aug 1987, 14:4, p. 51-6.

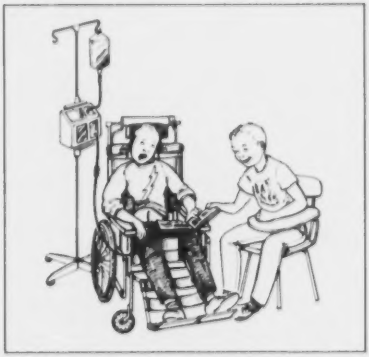
Care and maintenance of Hickman, Broviac and Leonard vascular access catheters: a nursing guide. 1986.
Cranston, RI: Davol Inc.
(800) 556-6275
Patient guide is also available.

Nursing guide to the care and maintenance of Hickman and Broviac catheters. 1986.
Video.
Cranston, RI: Davol Inc.
(800) 556-6275

Total parenteral nutrition manual: instructions for home administration. 1986.
Richardson DS.
Boston, MA: Children's Hospital.

Nursing care and management of venous access ports.
Moore CL, Erikson KA, Yanes LB, Franklin M, Gonsalves L.
Oncology Nursing Forum May-June 1986, 13:3, p. 35-9.

Long-term venous access.
Wilkes G, Vannicola P, Starck P.
American Journal of Nursing
July 1985, p. 793-796.



Gastrostomy Tubes

G-Tube as friend. 1991.
Developmental Evaluation Center.
Boston, MA: Children's Hospital.
(In the final stages of production at the time of going to print.)

Preparing families of children with gastrostomies.
Huddleston KC, Ferraro AR.
Pediatric Nursing Mar-Apr 1991, 17:2, p. 153-8.

Home gastrostomy care for infants and young children. 1990.
Video with accompanying manual.
University of Colorado Health Sciences Center.
Lawrence, KS: Learner Managed Designs, Inc.

Nutrition for your gastrostomy-fed child: a parent handbook. 1989.
Sondel S, Knickmeyer M.
Madison, WI: University of Wisconsin Hospital and Clinics.
Includes a listing of resources and associations.

Gastrostomies: indications, management and weaning.
Nelson CLA, Hallgren RA.
Infants and Young Children 1989, 2:1, p. 66-74.

MIC or Foley: comparing gastrostomy tubes.
Huddleston K, Vitarelli R, Goodmundson J, Kok S.
Maternal Child Nursing Journal Jan-Feb 1989, 14:1, p. 20-3.

Your personal guide to home tube feeding. 1989.
Norwich, NY: Norwich Eaton Pharmaceuticals, Inc.
(607) 335-2111

Tube feeding: parental perspective.
Campbell AL.
Exceptional Parent 1988, 18, p. 36-40.

Feeding gastrostomy. Part I. Indications and complications.
McGee L.
Journal of Enterostomal Therapy Mar-Apr 1987, 14:2, p. 73-8.

Feeding gastrostomy. Part II. Nursing care.
McGee L.
Journal of Enterostomal Therapy Sep-Oct 1987, 14:5, p. 201-11.

Pediatric adaptive technologies: gastrostomy tube feeding. 1986.
Video and workbook.
Zechman RAD, Ross A, Watkins J.
Seattle, WA: University of Washington.

Reinstituting oral feedings in children fed by gastrostomy tube.
Blackman JA, Nelson CLA.
Clinical Pediatrics Aug 1985, 24:8, p. 434-8.

Gastrostomy tubes: practical guidelines for home care.
Paarlberg J, Balint JP.
Pediatric Nursing Mar-Apr 1985, 11:2, p. 99-102.

Care of the child with a gastrostomy tube: common and practical concerns.
Perez RC, Beckom L, Jebara L, Lewis MA, Patenaude Y.
Issues in Comprehensive Pediatric Nursing 1984, 7, p. 107-19.

Gastrostomy Buttons

A button for gastrostomy feedings.
Huddleston KC, Palmer KL.
Maternal and Child Nursing Journal Sep-Oct 1990, 15, p. 315-9.

Feeding gastrostomy button: experience and recommendations.
Gauderer MWL, Olsen MM, Stellato TA, Dokler ML.
Journal of Pediatric Surgery Jan 1988, 23:1, p. 24-8.

The gastrostomy feeding button.
Huth MM, O'Brien ME.
Pediatric Nursing Jul-Aug 1987, 13:4, p. 241-5.

Care of a percutaneous endoscopic gastrostomy (P.E.G.) and the button replacement gastrostomy. 1987.
Bard Interventional Products.
(800) 826-BARD

Jejunostomy Tubes

Skin-level gastrostomies and jejunostomies for long-term enteral feeding.
Shike M, Wallach C, Gerdes H, Hermann-Zaidins M.
Journal of Parenteral and Enteral Nutrition Nov-Dec 1989, 13:6, p. 648-50.

Jejunostomy button as a new method for long term jejunostomy feedings.
Stellato TA, Gauderer MWL.
Surgery, Gynecology and Obstetrics Jun 1989, 168:6, p. 552-4.

ELIMINATION

Ostomy Care

Use of an ostomy pouch for pediatric CAPD swimmers.
Sandahl LL, Owens EL.
American Nephrology Nurses Association (ANNA) Journal Jun 1989, 16:4, p. 274-7.

Teaching ostomy care to the pediatric client: a developmental approach.
Erwin-Toth P.
Journal of Enterostomal Therapy May-Jun 1988, 15:3, p. 126-30.

Ostomy care and puppets too.
Hancock L.
Journal of Pediatric Health Care Nov-Dec 1988, 2:6, p. 320-1.

Ostomies: the art of pouching.
Erickson PJ.
Nursing Clinics of North America Jun 1987, 22:2, p. 311-20.

Life span changes: implications for ostomy care.
Motta GJ.
Nursing Clinics of North America Jun 1987, 22:2, p. 333-39.

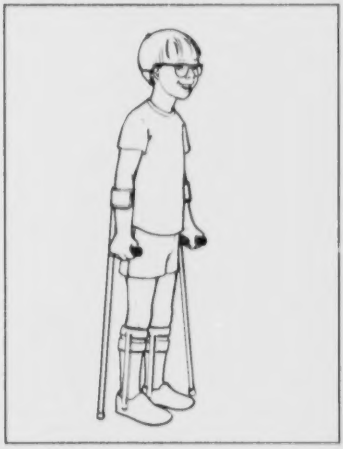
Children with ostomies: comprehensive care planning.
Adams DA, Selekof JL.
Pediatric Nursing Nov-Dec 1986, 12:6, p. 429-33.

These special children: the ostomy book for parents of children with colostomies, ileostomies and urostomies. 1982.
Jeter KF.
Palo Alto, CA: Bull Publishing Co.
Includes appendices: Resources that help; Ostomy appliances and incontinence aids.

Paediatric problems associated with stomas. Part 2: Special needs of paediatric patients.
Jeter KF.
Clinics in Gastroenterology May 1982, 11:2, p. 360-72.

The ostomy book: living comfortably with colostomies, ileostomies and urostomies. 1980. Mullen BD, McGinn KA.
Palo Alto, CA: Bull Publishing Co.

Clean Intermittent Catheterization



A practical approach to teaching self-catheterization to children with myelomeningocele.
Brown JP.
Journal of Enterostomal Therapy
1990, 17, p. 54-6.

Bowel and bladder management of the child with myelomeningocele in the school setting.
Smith KA.
Journal of Pediatric Health Care Jul-Aug 1990, 4:4, p. 175-80.

Clean intermittent catheterization. 1986.
Video with accompanying manual.
University of Colorado Health Sciences Center.
Lawrence, KS: Learner Managed Designs, Inc.

Clean intermittent catheterization - the law.
Glucksman J.
Spotlight Aug 1985.
Chicago, IL: Spina Bifida Association of America

RESPIRATORY

Oxygen Therapy

School placement and the oxygen-dependent child.
Wessel GL, Prumo MO, Harrison P.
Journal of Pediatric Nursing Dec 1989, 4:6, p. 435-6.

What patients on home oxygen want to know.
Openbirier DR, Fouss C, Mall C.
American Journal of Nursing 1988, 88:2, p. 198-201.

Home oxygen therapy. Evaluation and prescription.
Openbirier DR, Hoffman LA, Wesmiller SW.
American Journal of Nursing 1988, 88:2, p. 192-7.

Home oxygen for infants and young children. 1988.
Video and accompanying manual.
University of Colorado Health Sciences Center.
Lawrence, KS: Learner Managed Designs.

Nursing considerations for discharging children home on low-flow oxygen.
Paulson PR.
Issues in Comprehensive Pediatric Nursing 1987, 10, p. 209-14.

Home oxygen therapy for infants and children.
Givan DC, Wylie P.
Indiana Medicine Oct 1986, 79:10, p. 849-53.

A guide to your patients' home use of oxygen.
Ellmeyer P, Thomas NJ.
Nursing '82 1982, p. 56-7.

Preparing the family for home tracheostomy care.
Ronczy NM, Lichtenstein Beddome MA.
AACN - Clinical Issues in Critical Care Nursing Aug 1990, 1:2, p. 367-77.

Your child has a tracheostomy: a guide for home care. 1990.
Crimlisk JT, Murray SV, Judas ML, Jorgensen KM, Thompson JA.
Department of Health and Hospitals.
Boston, MA: Boston City Hospital.
(617) 534-4030

Development of a preschool program for tracheostomy dependent children. *See page 16.*

The decannulation process in children.
Runton N, Zazal GH.
Journal of Pediatric Nursing Oct 1989, 4:5, p. 370-3.

Tracheostomy in young children: implications for assessment and treatment of communication and feeding disorders.
Simon BM, McGowan JS.
Infants and Young Children 1989, 1:3, p. 1-9.

Home tracheostomy care for infants and young children. 1989.
Video and accompanying manual.
University of Colorado Health Sciences Center.
Lawrence, KS: Learner Managed Designs, Inc.

Gaining access to school for the child with a tracheostomy.
Grundfast KM, Runton N, Loeffel-Wines M.
International Journal of Pediatric Otorhinolaryngology 1988, 16, p. 101-12.

Tracheostomy care: parents as learners.
Kennelly C.
Maternal and Child Nursing Journal Jul-Aug 1987, 12:4, p. 264-7.

Hospital to home care of the child with a tracheostomy.
Kenney M.
Neonatal Network 1987, p. 21-4.

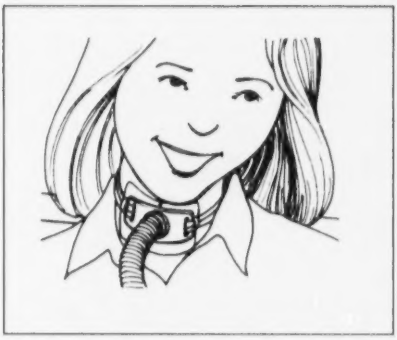
Tracheostomy home care for children. 1987.
Kun S, Halvorson M, Liebhauser P.
Department of Nursing.
Los Angeles, CA: Children's Hospital.
(213) 660-2450

Pediatric home tracheostomy care: a parent's guide.
Lichtenstein MA.
Pediatric Nursing Jan-Feb 1986, 12:1, p. 41-8, 69.

An educational program for families of children with tracheostomies.
Kennedy AH, Johnson WG, Sturdevant EW.
Maternal and Child Nursing Journal 1982, 7, p. 42-9.

Tracheostomy care. 1981.
Lyons RJ, Yuska CM.
Irvine, CA: Shiley Incorporated.
(800) 854-3683

A guide to pediatric tracheostomy care. 1981.
Adamo P.
Springfield, IL: Charles C. Thomas.
Written for parents and families.



Home care of the ventilator-dependent child.
Lynch M.
Children's Health Care
Summer 1990, 19:3, p. 169-73.

Home care for ventilator-assisted children: predicting family stress.
Wegener DH, Aday LA.
Pediatric Nursing Jul-Aug 1989, 15:4, p. 371-6.

A study of pediatric home ventilator management: medical, psychosocial and financial aspects.
Hazlett DE.
Journal of Pediatric Nursing Aug 1989, 4:4, p. 284-94.

Problems in respiratory care, mechanical ventilation in the home: issues for health care providers. 1988. Vol. 1, No. 2.
Gilmartin M and Make B, eds.
Philadelphia: JB Lippincott Company.

Louisiana's ventilator assisted care program: case management services to link tertiary with community-based care.
Kirkhart KA, Steele NF, Pomeroy M, et al.
Children's Health Care 1988, 17:2, p. 106-11.

Community care: pediatric home mechanical ventilation.
Donar ME.
Holistic Nursing Practice 1988, 2:2, p. 68-80.

The ventilator-dependent child: challenge and opportunity.
Posch CM, Edwards PA.
Rehabilitation Nursing Jan-Feb 1988, 13:1, p. 15-8.

Ventilators and muscular dystrophy. 1987.
Schock NC, Colbert AP.
St Louis, MO: Gazette International Networking Institute.
(314) 361-0475

Quality of care for life-supported children who require prolonged mechanical ventilation at home.
Goldberg AI, Noah Z, Fleming M, Staniek L, Childs B, Frost L, Glynn W.
Quality Review Bulletin Mar 1987, 13:3, p. 81-8.

Pediatric home mechanical ventilation.
Schreiner MS, Donar ME, Kettrick RG.
Pediatric Clinics of North America 1987, 34:1, p. 47-60.

Getting it started and keeping it going: a guide for respiratory home care of the ventilator assisted individual. 1987.
Manual with accompanying video.
Ventilator Assisted Care Program and Respiratory Care Department
New Orleans, LA: Children's Hospital.

Ventilator-assisted patient care: planning for hospital discharge and home care. 1986.
Johnson D, Giovannoni R, Driscoll S.
Baltimore, MD: Aspen Publications.

Long-term mechanical ventilation: guidelines for management in the home and at alternate community sites.
O'Donohue WJ, Giovannoni RM, Goldberg AI, Keens TG, Make BJ, Plummer AL, Prentice WS.
Chest Jul 1986 Supp., 90:1, p. 1S-37S.

A home discharge program for ventilator-assisted children.
McCarthy MF.
Pediatric Nursing Sep-Oct 1986, 12:5, p. 331-5, 380.

Outcome of home mechanical ventilation in children.
Frates RC, Splaingard ML, Smith EO, et al.
Journal of Pediatrics 1986, 106, p. 850-6.

Homeward bound: resources for living at home with a chronically ill child. 1985.
Ventilator Assisted Care Program.
New Orleans, LA: Children's Hospital.

Home care for ventilator-dependent children: providing a chance to live a normal life.
Lawrence PA.
DCCN: Dimensions of Critical Care Nursing Jan-Feb 1984, 3:1, p. 42-52.

Guidelines for home care of responauts: Task Force report. 1984.
Division of Services to Crippled Children.
Lansing, MI: Michigan Department of Public Health.

Home care for children on respirators.
Burr BH, Guyer B, Todres ID, Abrahams B, Chiodo T.
New England Journal of Medicine 1983, 309, p. 1319-23.

EQUIPMENT

The development of pediatric standards of care for home medical equipment supplier.
Kostel A, Cooper L, Mahoney K, Solem G.
Caring 1991, 10:11, p. 64-67.

The Passy-Muir tracheostomy speaking valve video demonstration. 1990 edition.
Video.
Irvine, CA: Passy & Passy Inc.
(714) 856-2634

LP6 Volume Ventilator: clinician's guide. 1990.
Manual with accompanying video.
Minneapolis, MN: Aequitron Medical Inc.
(800) 824-7203

Introduction to the Companion 2801 volume ventilator. 1990.
Video.
Lenexa, KS: Puritan Bennett.
(800) 248-0890 (press 3)
or (913) 469-5400

Respiratory home care equipment. 1988.
McPherson S.
Dubuque, IA: Kendall/Hunt Publishing Company.

LP6 Volume Ventilator: user's guide. 1988.
Manual with accompanying video.
Minneapolis, MN: Aequitron Medical Inc.
(800) 824-7203

Passy-Muir tracheostomy speaking valve.
Passy V.
Otolaryngology 1986, 95:2, p. 247-8.

Olympic Medical
4400 Seventh South
Seattle, WA 98108
(800) 426-0353
Supplier of Olympic Trach-Buttons

J. H. Emerson Co.
22 Cottage Park Ave.
Cambridge, MA 02140
Manufacturer of the Emerson Chest Respirator

Center Laboratories
35 Channel Drive
Port Washington, NY 11050
Manufacturer of the EpiPen Training Device, an auto-injection simulator.

HELPFUL MATERIALS FOR TRAINING COMMUNITY PERSONNEL

When carrying out a training program, it is often appropriate to have handouts that augment and provide examples for the session. In this section, we list materials which present topics for a general audience and can be used as helpful adjuncts to training programs for parents, teachers and other personel.

Getting on board: training activities to promote the practice of family-centered care. 1991.
Edelman L, ed.
Bethesda, MD: Association for the Care of Children's Health (ACCH).

Your child has a disability. A complete sourcebook of daily and medical care. 1991.
Batshaw M.
Boston, MA: Little, Brown and Co.

How it feels to fight for your life. 1989.
Krementz J.
Boston, MA: Little, Brown and Co.

Strategies for working with culturally diverse communities and clients. 1989.
Randall-David E.
Bethesda, MD: Association for the Care of Children's Health.

Serving culturally diverse families of infants and toddlers with disabilities. 1989.
Anderson P, Fenichel E
Washington DC: National Center for Clinical Infant Programs

Working together: the parent/professional partnership. 1987.
Regional Research Institute for Human Services.
Portland, OR: Portland State University.
Trainer's guide for a one-day workshop on collaboration and cooperation.
(503) 725-4040

Strategies: a practical guide for dealing with professionals and human service systems. 1987.
Shields CV.
Baltimore, MD: Paul H. Brookes Publishing Co., Inc.

High tech home care: a practical guide. 1987.
Haddad AM.
Creighton University, Nebraska.
Rockville, MD: Aspen Publishers, Inc.
Includes appendices: AIDS support organizations and information sources.

Family-centered care for children with special health care needs. 1987.
Shelton TL, Jeppson ES, Johnson BH.
Bethesda, MD: ACCH
Includes appendix: Family-centered care resources

The family as care manager: home care coordination for medically fragile children. 1986. Workbook series for providing services to children with handicaps and their families.
Kaufman J, Lichtenstein K.
Georgetown University Child Development Center.
Coordinating Center for Home and Community Care, Inc.
Millersville, MD.
(301) 621-7830 or (410) 987-1048.

Meeting the challenge of disability or chronic illness: a family guide. 1986.
Goldfarb LA, Brotherson MJ, Summers JA, Turnbull AP.
Baltimore, MD: Paul H. Brookes Publishing Co.

Home care for the chronically ill or disabled child: a manual and sourcebook for parents and professionals. 1985.
Jones ML.
New York, NY: Harper & Row, Inc.
Includes appendices: Suggested readings; Helpful organizations.

A difference in the family: life with a disabled child. 1980.
Featherstone H.
New York, NY: Basic Books, Inc.

HEALTH / EDUCATION

Comprehensive curriculum guidelines on HIV/AIDS: Grades K-12. 1991.
Robinson C.
Bureau of Parent, Child and Adolescent Health.
Boston, MA: Massachusetts Department of Public Health

Health care for students with disabilities: an illustrated medical guide for the classroom. 1990.
Graff JC, Ault MM, Guess D, Taylor M, Thompson B.
University of Kansas.
Baltimore, MD: Paul H. Brookes Publishing Co.

Integration checklist: a guide to the full inclusion of students with disabilities.
New Hampshire Challenge.
Family Support Bulletin, United Cerebral Palsy Association, Summer 1990, p. 8-9.

Criteria for integration: what makes integration work?
Strategies...a part of the TASH Dissemination Project, 1989.
Family Support Bulletin, United Cerebral Palsy Association, Summer 1990, p. 10.

Guidelines for the delineation of roles and responsibilities for the safe delivery of specialized health care in the educational setting. 1990. *See page 11.*

Choosing a school for your child. 1989.
Perkins-Weston S.
Washington DC: U.S. Department of Education.
For free copy:
Choosing a School
Consumer Information Center
Pueblo, CO 81009
Includes appendix: Sources of additional information.

Young people with cancer: a handbook for parents. 1988.
NIH pub.# 88-2378.
U.S. Department of Health and Human Services.
Bethesda, MD: National Cancer Institute.
Includes foldouts, list of additional reading materials.

Barron's first aid for kids. 1987.
Fleisher G.
Children's Hospital Boston.
Hauppauge, NY: Barron's Educational Series, Inc.

Students with cancer: a resource for the educator. 1987.
NIH pub.# 87-2086.
Washington DC: U.S. Department of Health and Human Services.
Includes selected bibliographies for educators, young people; information on Candelighters Foundation (2025 Eye Street, NW, Suite 1011, Washington DC 20006),
Cancer Information Service (1-800-422-6237).

Children with handicaps: a medical primer. 2nd ed, 1986.
See page 13.

Nutrition and feeding for the developmentally disabled: a how-to manual. 1985.
Office of Child & Adult Nutrition Services
Pierre, SD: South Dakota Department of Education and Cultural Affairs

Selecting equipment vendors for children on home care.
Hartsell MB, Ward JH.
Maternal Child Nursing Journal Jan-Feb 1985, 10, p. 26-8.

Medical problems in the classroom: the teacher's role in diagnosis and management. 1983.
Haslam RHA, Valletutti PJ, eds.
Baltimore, MD: University Park Press.

Physically handicapped children: a medical atlas for teachers.
2nd ed, 1982.
Bleck EE, Nagel DA.
Stanford University School of Medicine.
Orlando, FL: Grune & Stratton, Inc.

INFORMATION ON FINANCING

Ensuring access. Family-centered health care financing systems for children with special health needs. 1991.
New England SERVE
101 Tremont Street
Boston, MA 02108.
(617) 574-9493.

Health care financing for severe developmental disabilities. 1991.
Birenbaum A, Guyot D and Cohen H.
Annapolis Junction, MD: AAMR Publications.

What has the Social Security Administration done for you lately? Maybe more than you know.
Owen MJ.
Exceptional Parent June 1991, p. 40-2.

Medicaid and other third-party payments: one piece of the early intervention financing puzzle. 1990.
White KR, Immel N.
Bethesda, MD: Association for the Care of Children's Health.
Includes appendix: Resources for developing a system to use third-party payments to support early intervention programs; includes both a listing of printed materials and technical assistance/ consultation resources.

Special needs, special solutions: how to get quality care for a child with special health needs. A guide to health services and how to pay for them. 1990.
Larson G, Kahn JA.
St. Paul, MN: Lifeline Press.

Understanding Medicaid coverage. 1989.
Boston, MA: Federation for Children with Special Needs.
(617) 482-2915

Health care financing: a guide for families. 1989
Beckett J.
Iowa City, IA: National Maternal and Child Health Resource Center.
To order: National Maternal and Child Health Resource Center,
Law Building, University of Iowa,
Iowa City, Iowa 52242.

Understanding your health insurance options: a guide for families who have children with special health care needs. 1988.
McManus MA.
Washington DC: McManus Health Policy, Inc.

Financing health care for disabled children.
Newacheck PW, McManus MA.
Pediatrics Mar 1988, 81:3, p. 385-94.

Health care coverage for the child with a chronic illness or disability: a funding source catalog for Wisconsin. 2nd ed, 1988.
Gaylord C, Leonard A.
Madison, WI: Center for Public Representation.

State Medicaid manual: early and periodic screening, diagnosis and treatment (EPSDT). 1988.
Health Care Financing Administration.
Washington DC: Department of Health and Human Services.
(319) 335-9067

Technology-dependent children: hospital v. home care.
A technical memorandum. 1987. *See page 12.*

Meeting the medical bills. 1986.
Video.
Arlington, VA: National Center for Clinical Infant Programs.
(800) 999-5599

Funding strategies; advice to parents.
Galten R.
Caring May 1985, 4:5, p. 54, 56-7.

Innovative approaches to financing home care.
Bilotti E, Kettrick R.
In: Home Care for Children with Serious Handicapping Conditions. A report on a conference sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health, Public Health Service, U.S. Department of Health and Human Services 1984, p. 86-91.
Bethesda, MD: Association for the Care of Children's Health.

TRANSPORTATION

School bus safety.
Stroup K, Stout J, Atkinson B, Doll J, Russell R.
Exceptional Parent 1991; 21:6, p. 80.

Supervisor's guide for transporting children with special health needs. 1991. *See page 22.*

The effective driver of handicapped students. 1990.
Korn G, Korn JA.
Kingston, NH: SAFEWAY Training & Transportation Services, Inc.
(603) 642-3642

Special transportation health care for drivers & assistants. 1989.
Department of Continuing Health Education.
Lansing, MI: Lansing Community College.

The challenge of transporting children with special needs. 1989.
Richards DD.
American Academy of Pediatrics.
Safe Ride News, Spring 1989, special insert.

CHAPTER 4 RESOURCE ORGANIZATIONS

The staff of Project School Care have learned through our work in the community that some of the richest resource materials are the various local, state and federal organizations serving children with disabilities and their families. Readers who are planning training programs should involve their local and state departments of Public Health and Education. Often, they have resource teams who specialize in technical assistance and training. In addition, the organizations listed below have libraries, training videos and other instructional materials which may enhance the training process.

The following organizations provide and/or publish information on a variety of topics. Contacting the organization directly is the best way to obtain a complete listing of their publications and resources.

LOCAL RESOURCE

Contact your local public library to see if they subscribe to:
Data Base Med-Line.
A computerized database that has information covering medical publications about research, treatment, information and studies done on specific disorders, diseases and conditions. Fees vary.

STATE CONTACTS

Contact the following agencies in each individual state to request training and reference materials:

Department of Education
Department of Public Health
State Coordinating Councils for Early Intervention

NATIONAL ORGANIZATIONS

Alliance of Genetic Support Groups
1001 22nd Street, N.W. - Suite 800
Washington DC 20037
(800) 336-GENE
(202) 331-0942
FAX: (202) 293-0479
Alliance is a national non-profit coalition of more than one hundred member organizations, each of which provide support and information for people affected by a variety of genetic disorders. The Alliance provides referrals, publishes a newsletter and maintains listings of state agencies and resources. This organization serves both consumers and professionals.

Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549
ACCH is a non-profit organization for parents and professionals who work with children with special medical needs. The organization has regional affiliates, who promote education and advocacy. ACCH publishes a newsletter and an annual resource catalogue, which lists many of their publications and videos. ACCH also sponsors conferences and publishes books, booklets and videos on a range of topics related to the health care of children and their families.
Examples of recent publications:
"Your child with special needs at home and in the community"
"Getting on board: training activities to promote the practice of family-centered care"

Association of Birth Defect Children (ABDC)
5400 Diplomatic Circle, Ste 270
Orlando, FL 32810
(407) 629-1466
ABDC is a national non-profit organization which provides support and information for families of children with birth defects believed to be caused by the mother's exposure to drugs, radiation, chemicals, pesticidies or other environmental agents. They publish a quarterly newsletter and offer a free clearinghouse, answering requests for information and helping parents get in touch with specific support groups.

Caring Magazine
National Association for Home Care
519 C Street NE/Stanton Park
Washington DC 20002
(202) 542-8600
Caring is a monthly magazine for the home care field. It features articles, analysis, special sections and departments covering all aspects of the field, both nationally and internationally ($45 per year).

Child Welfare League of America, Inc. (CWLA)
220 First St, NW, Ste 310
Washington DC 20001-2085
(202) 638-2952
CWLA has a variety of publications, including different newsletters, journals, reports and updates, and books. Local agencies across the country can also join CWLA's membership program and gain access to the latest information on child welfare issues, help influence public policy and legislation and much more. In addition, CWLA sponsors conferences and has a training institute that provides training on a number of issues pertaining to children.

Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091
(703) 620-3660 voice & TDD
(703) 264-9494 FAX
CEC is a national professional organization whose goal is to improve education for all exceptional children, gifted and handicapped. CEC has an annual convention, holds conferences, publishes Children and TEACHING Children, prints an annual catalogue of publications and provides support to professionals. The **ERIC Clearinghouse on Handicapped and Gifted Children**, a division of the CEC, operates a national educational database and prepares research reviews. ERIC can be reached at (703) 264-9474.

DREDF/Disability Rights Education and Defense Fund, Inc.
2212 6th Street
Berkeley, CA 94710
(415) 644-2555
DREDF is a national center which focuses on law and policies related to the civil rights of people with disabilities. They offer services of legal and education advocates, as well as public speakers on various topics. They also publish a newsletter.

Exceptional Parent Magazine
P.O. Box 3000, Dept. EP
Denville, NJ 07834
(800) 247-8080 (subscriptions; $18 per year)
(800) 852-2884 (advertising office)
The annual September edition lists a variety of parent resource groups, government agencies, professional organizations and special information and support groups for a variety of special needs.

Family Resource Coalition
200 South Michigan Ave., Suite 1520
Chicago, IL 60604
312/341-0900
312/341-9361 FAX
The Coalition is a national, non-profit organization which represents community-based family resource programs. Its membership is professionally diverse and seeks to build programs at the community level. Focal points of the group are program building, legislative support and funding support.

Federation for Children with Special Needs
95 Berkeley Street
Suite 104
Boston, MA 02116
(800) 331-0688
(617) 482-2915
The Federation, organized as a coalition of parent groups, represents children with a variety of disabilities and acts as a child advocacy and information center. They offer a variety of services, including: assistance, written materials and workshops for parents and professionals on a variety of topics relating to children with special health needs. In addition, the federation publishes a quarterly journal. The Federation also operates **CAPP/National Parent Resource Center,** a parent-run system designed on the principle of family-centered, community-based care for children with special health care needs and their families. For more information, contact the regional office nearest you.

Central Office
CAPP/Center
Federation for Children with Special Needs
95 Berkeley Street, Ste 104
Boston, MA 02116
(617) 482-2915

Midwest Regional Center
PACER Center
4826 Chicago Avenue
Minneapolis, MN 55417
(612) 827-2966

South Regional Center
PEP, Georgia ARC
1851 Ram Runway #104
College Park, GA 30337
(404) 761-3150

Northeast Regional Center
Parent Information Center
P.O. Box 1422
Concord, NH 03301
(603) 224-0402

West Regional Center
Washington PAVE
12208 Pacific Hwy, SW
Tacoma, WA 98499
(206) 588-1741

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 01240
(617) 876-0426
Example of recent publication:
"Support for families of people with a disability: bibliography and resource guide"

Learner Managed Designs, Inc.
2201 K West 25th Street
Lawrence, KS 66047
(913) 842-9088
Professional training resources, including books, software and videos are available on a variety of topics related to children with special needs. Call to request a catalogue.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100
March of Dimes offers information over the phone as well as copies of materials about specific disorders and rare conditions. They also refer to support organizations and other agencies for information.

MUMS: Mothers United for Moral Support, Inc.
c/o Julie Gordon
150 Custer Court
Green Bay, WI 54301
(414) 336-5333
MUMS is a national support and referral group for parents of children with disabilities and delays. Membership includes both parents and professionals. A database service is available to direct people to support groups which address specific disabilities.

National AIDS Hotline
(800) 342-AIDS
(800) 344-SIDA (Spanish access)
(800) AIDS-TTY (Deaf access)
Toll-free hotline which provides education, information and referrals.

NAIC: National AIDS Information Clearinghouse
P.O. Box 6003
Rockville, MD 20850
(800) 243-7012 TTY/TDD
(301) 738-6616 FAX
Provides custom database search services, information and resources and publications to interested persons.

National Association of School Nurses
P.O. Box 1300
Scarborough, ME 04070-1300
(207) 883-2117
NASN, an affiliate of the National Education Association (NEA), is a non-profit organization committed to providing quality school health services for children. The organization stresses professionalism and organization and views the role of school nurse as that of a liaison between school, community and home. The group provides support, education and publications for its members.

National Center for Education in Maternal and Child Health
520 Prospect Street, NW
Washington DC 20057
(202) 625-8400
Formerly the National Clearinghouse for Human Genetic Diseases, the Center continues to provide information and resources on genetic disorders. It also publishes a guide on starting a self-help group for a genetic illness.

National Center for Education in Maternal and Child Health / National Maternal and Child Health Clearinghouse (NCEMCH/ NMCHC)
38th and R Streets, NW
Washington DC 20057
(202) 625-8400 (NCEMCH)
(202) 625-8410 (NMCHC)
These "sister" organizations respond to general information requests, publish documents and pamphlets on a variety of topics and provide educational information on topics specifically relating to maternal and child health. A catalogue listing their publications is also available. Both health professionals and consumers are served.

National Center for Youth with Disabilities
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(800) 333-6293
(612) 624-3939 Voice & TDD
The National Center is an information and resource center for adolescents, families and professionals. Services include: information and referrals, annotated bibliographies, fact sheets, a quarterly newsletter and a central database in the National Resource Library. The focus of the Center is the lifestyle, transitional and psychosocial needs of adolescents who are living with chronic illness or disabilities.

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
(800) 221-6827
This organization publishes information on all types of physical disabilities, including genetic disorders. They will distribute a list of publications upon request.

National Early Childhood Technical Assistance System (NEC*TAS)
University of North Carolina at Chapel Hill
CB# 8040
500 NCNB Plaza
Chapel Hill, NC 27599
(919) 962-2001
NEC*TAS assists states and other designated governing entities in developing multi-disciplinary, coordinated and comprehensive services for children, from birth to eight years of age, with special health needs. NEC*TAS provides materials, information referrals and a networking system to parents and other professionals.

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington DC 20013
(800) 999-5599
(703) 893-6061
NICHCY assists parents, educators, caregivers and others in ensuring that all children and youth with disabilities have a better opportunity to reach their fullest potential. NICHCY will address individuals' questions as well as provide referrals to other organizations, information packets, publications and technical assistance to parent and professional groups. A newsletter is published three times a year.

National Information Center for Orphan Drugs and Rare Diseases (NICODARD)
P.O. Box 1133
Washington DC 20013-1133
(800) 456-3505
NICODARD, of the National Health Information Clearinghouse, responds to questions on rare disorders using NHIC's computer database and library.

National Information Clearinghouse
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(800) 922-9234, ext. 201
(800) 922-1107 in SC
The Clearinghouse is an information and referral service for parents and professionals who work with medically fragile infants and children from birth through age three. Information specialists at the toll-free number provide both local and national referrals.

National Information System (NIS) For Health Related Services
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(800) 922-9234
NIS for Health Related Services has trained counselors to answer your questions about medical, educational, rehabilitation, diagnosis, treatment and support for families and children, ages 0-21, with developmental and/or special health care needs.

National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-4000
The National Institutes of Health comprise 20 institutes, each dedicated to research and treatment of specific areas of disorders, including: Genetics and Teratology (birth defects), Endrocrinology, Nutrition and Growth, Mental Retardation and Developmental Disabilities, Arthritis, Allergies, Infectious Disease and many more. Treatment and publications are free.

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812
(203) 746-6518
NORD is a national information and referral service for parents and consumers who are concerned with medical and legislative issues associated with rare or "orphan" diseases. The organization publishes a newsletter, holds conferences and provides reprints of articles on particular diseases from its database. Contact the organization for an order form and listing of diseases and referral agencies.

National Parent Network
1600 Prince Street, Suite 115
Alexandria, VA 22314
(703)684-6763
A member organization open to all agencies, organizations, parent centers and groups, professionals and invidividuals concerned with quality of life issues for people with disabilities.

National Pediatric HIV Resource Center
Children's Hospital of New Jersey
15 S. Ninth Street
Newark, NJ 07107
(201) 268-8251
(800) 362-0071
(201) 485-7769 FAX
The HIV Resource Center is primarily a training and consultation source for medical professionals who work with children who are HIV+. A special training program, "Train the Trainer," is designed specifically for nurses who work with these children.

Pathfinder Resources, Inc.
2324 University Avenue W.
Suite 105
St. Paul, MN 55114
(612) 647-6905
(612) 647-6908 FAX
Examples of recent publications:
"Child Link" - Newsletter for SPRANS grant recipients and others serving children with special health care needs.
"Improving state services for culturally diverse populations: focus on children with special health needs and their families."

SKIP, Inc. / Sick Kids (Need) Involved People
National Headquarters
990 Second Avenue
New York, NY 10022
(212) 421-9160
SKIP is a national non-profit organization which provides information and services to families and professionals who work with children who are assisted by medical technology. Local chapters provide support while the national organization provides advocacy and legislative assistance. SKIP also has a recreational camp, called SKIPCamp; information is available from the national organization.

The Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115
(206) 523-8446
TASH is an international non-profit organization with a family and professional membership of over 6,700. Their purpose is to provide education about and advocacy for persons with severe cognitive disabilities and to support collaboration among all who work with these individuals. TASH sponsors an annual conference, publishes a newsletter and journal and has local chapters which provide educational and legislative support.

The Kids on the Block, Inc.
9385-C Gerwig Lane
Columbia, MD 21046
(301) 290-9095
(800)368-Kids
Features life size puppets designed to teach children and adults about what it is like to be handicapped and what it is like to be different. There are over 30 different puppets who talk about topics such as deafness, blindness, spina bifida, cerebral palsy, child abuse and epilepsy. They have been used all over the world and there are active programs in 49 states and 16 countries.

United Ostomy Association, Inc.
36 Executive Park, Suite 120
Irvine, CA 92714
(714) 660-8624
UOA is a national non-profit organization which supports more than 600 local chapters nationwide. It is a member of the International Ostomy Association. Local chapter volunteers hold regular meetings, visit patients and provide education and support to members and interested parties. A newsletter and various publications are also available.

Project School Care, directed by Judith S. Palfrey, M.D., is a program of Children's Hospital, Boston established to document and foster access to educational opportunities by children who are assisted by medical technology.

Project School Care offers services in consultations, training, and information in Massachusetts and nationally.

For information:
Project School Care
Gardner 610
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
(617) 735-6714
(617) 735-7940 (fax)